

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

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African American , Higher Education

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SECTION I: GENERAL IMMUNIZATIONS AND HEALTH CARE

There were 9 respondents in this higher education group. Of the nine, there were 3 males and 6 females. Check-ups, physical activity, improving eating habits and reading were the ways most of the respondents took care of themselves.

I. Prevention

The diseases that concerned the respondents as parents included childhood diseases as well as chronic diseases.

- Chicken pox
- Polio
- Measles
- Mumps, Rubella
- AIDS
- Tuberculosis
- Cancer
- Hepatitis
- Lupus
- Leukemia

II. Immunization

A *Reasons not to get vaccinated*

The respondents in the groups seemed pro-immunization but were able to come up with a long list of reasons others might not immunize their children. By category, these seemed to be including lack of education, fear of a negative outcome, cost, loss of confidence in the medical community, and religion. Some of the comments illustrating these categories included:

- Lack of education

Their pre-conceived conceptions.

Sometimes their parents think it's wrong. They didn't get the shot whatever, so they're going to say no.

- Fear of negative outcome

Fear of the child coming down with the disease.

The needles and all of that. It might turn out to be something else.

A bad batch of the inoculations.

Pain.

- Cost

Lack of health coverage.

A lot of people don't know that it's free. They think you got to pay for it.

- Loss of confidence in medical community. Participants talked about this loss of confidence in relation to chicken pox.

You hear different things.

And then I've had doctors tell me they wouldn't recommend it.

My pediatrician told me just let him go through it.

B. Reasons to get vaccinated

The health of the child and compliance with laws and policies seemed to be the key reasons that respondents believed that people have their children immunized. The reasons mentioned are listed below:

Protection.

Prevention.

You want them to be healthy.

State law requirements.

Knowledge.

Admission for school.

C. Ways parents are reminded of vaccine schedule

Respondents agreed that they were informed of the immunization schedule when their child was born. A chart with the schedule was cited as one of the pieces of information given at that time. A few were diligent about keeping it for their first child. Others relied on their own memory or a notice from the pediatrician or the school.

They give you an immunization schedule.

With my first I did [keep a chart] and then I just learned certain months, every 3 months as a matter of fact.

Some pediatricians will give you a notice.

They [the schools] send you a notification. Also the schools want you to bring in that booklet, that's why I have all of mine.

My kids have grown to let me know, when we go to the doctor, do I get a shot today and that jogs my memory.

D *Methods of tracking*

A few of the parents are keeping their own records. Others seem to obtain records when required for school or other reasons. Respondents did not seem to be highly involved in immunization record keeping.

SECTION 2: IMMUNIZATION REGISTRIES

I. *Initial reactions to the idea of a registry*

- The initial reaction to the idea of the immunization registry was favorable. There was no prior awareness of the registry. Respondents described it as a convenience for both parents and health care providers. In addition, for parents of more than one child it was described as a way to minimize confusion.

The parents don't really have to think about what to do next or if they change health care providers or move to a different state. It seems like it's pretty much done for you and it can travel with you from state to state and doctor to doctor.

You got an appointment for this one and the doctor can't fit you in and he reschedules you and he forgets. He has another doctor that's in there, who's going to substitute to see your kid, you kind of lose track. To me it's like a fail safe, it's a back up system where you go to your regular doctor's office.

They keep you informed. Their job is to help you and they keep sending you out things to keep you informed about immunizations.

- The idea was well received, but it was not without criticism. A key issue was confidentiality.

Invasion of privacy. Is it only going to be limited to immunizations?

- After discussing the registry, one respondent believed that she had, in fact, had an experience with the registry in the past month.

My son went to the doctor's maybe a month ago and I needed a copy for camp and she wanted to take it off the book. I had the book but she said that's okay. She did a form on

the computer and all of his shots, the dates and all was on the paper. ... they just gave me a printout from the computer.

- There was also a question of usefulness for some respondents. There were those who kept records who believed that the registry would be more helpful for less diligent parents. Less stable parents were also believed to benefit from this type of program.

Basically I know my doctor, she writes the lot number in the books.

If you stay with the same pediatrician until your child is 18 years old, you have a record right there, but there are so many people that run from place to place that they're the ones that need this.

II. Content of the registries

A. Initial reactions to the type of information typically in a registry

- Generally the information to be included in the registry generated a neutral to favorable reaction. Respondents immediately focused on the value of having a lot number. However, they questioned how a parent could be notified given the absence of address or phone number. Suggested additions included the name of the doctor and a way to contact the parent.
- The required information was believed to be useful and purposeful.

The top portion of this would probably be good if your child had a reaction.

I think all the information contained in the first section is really good, but I would add the name of the doctor.

It's also a good safety net. Just in case, you look at the days and they have a recall if your child's been vaccinated. Instead of calling, what was that lot number? You have that information right there at your fingertips you know if something was to break out or your child got a bad case of medicine.

- The necessity of information related to the mother's maiden name and the child's gender were questioned. In addition, the lack of a point of contact was also mentioned.

Why would it be just the mother's name?

Why do they need my child's gender?

B. Reactions to including home address and phone numbers

- Prior to the introduction of the possibility of an address and phone number, respondents saw no way to be contacted should there be a need.

How are they supposed to contact you? I see no way for them to contact me. If something is wrong with this batch of medicine, how are they going to contact me?

I think there needs to be a little bit more information in the even that they do need to contact you, but at the same time that's going to privacy issues because I would be comfortable if it included like maybe the child or parents address but not telephone number and Social Security number.

- Once the possibility of including an address and phone number was introduced, respondents raised issues related to the mobility of the population. People move so much that the addresses might quickly become obsolete. In addition, who assumes the responsibility for reporting a change of address was raised.

That's [home and address] not a concrete thing. I don't think you could really go with that.

That would be my main concern, once I decide to change my child's pediatrician, is it going to be their responsibility to update it or will it be my responsibility?

C *Reactions to including parent or child social security number*

- Prior to introducing the idea that the social security number would be included respondents were more comfortable with the information to be included in the registry.

I don't think too much can go wrong with this because they're not asking for Social.

I would be comfortable if it included like maybe the child or parents address but not telephone number and Social Security number.

- After the explicit question of including the social security number respondents questioned the purpose given the other information listed on the child. The most troubling issue for the respondents appeared to be the potential for invasion of privacy.

Social Security number, they can pull up anything you want about you.

You throw that in, not only do you have the child, you got the mother, you got everything.

They could take your identity.

D. *Reactions to including health care members enrollment (WIC, Medicare numbers)*

Respondents saw no merit in adding health care enrollment numbers to the registry. In addition, they saw the potential to do more harm than good.

Too much information.

The Government can go in-any different agency within the State government if they want to do something, you already there, you're in the database.

Distrust.

III. Access

A. Who should have access

- Respondents clearly expressed the need for limits on who should have access to the information in the registry.

As long as there are those limits as far as the access to the information, as long as they are there, I think it's a good idea because it helps to simplify things not only for the parents but the health care providers.

- Respondents did not agree completely on who should have access to the information. The least controversial was the doctor who has direct contact with the child and the parent. Some believed that nurses and the school system should also have access.

B Who should not have access

- Generally, those with more of a public health interest than a direct interest in the child were those for whom respondents would restrict access. Specifically, this would include:

- Pharmaceutical companies
- Scientists
- Researchers
- Pharmacists

- Some respondents did not believe that the school system should have access. The recommended source of the school system's information was said to be the parents.

I don't think the school system should be involved. I want them to come to me if they think my child has not had something.

- Respondents also objected to health insurers having access. Key concerns were related to having health benefits canceled or having the cost of health care increase.

It could be used against you. We're saying that our ethnic people are not getting their well baby care shots, so let's up the premiums.

It could be a glitch, oh your child's not getting well baby care, guess what, we can drop him off your health care.

C. *Reactions to ideas of linking registry by computer to other health information systems*

Respondents saw no benefit in linking other health systems to the immunization registry. In fact, the idea generated an unfavorable reaction primarily because respondents were concerned about who could end up with the information and how it could be used. There seemed to be a feeling that there was the potential for more harm than good.

I feel as though it's too much information being passed on to different links. It's going through too many hands.

It's a privacy issue.

I just don't understand the correlation between somebody's immunizations and if you dealing with lead poisoning or some of those other things. You're dealing with WIC, that's a stretch but getting into some of the other categories, there's no need for that.

In my opinion, that's getting away from the central purpose of the registry. I think that's a bad idea.

Preventive health care versus accidental.

IV. *Consent and inclusion*

A. *Reactions to "opting out"*

- Some of the issues related to "Opting Out" were based on the perception that notification would be through the mail.

Too many things can happen like you never see the notice for whatever reason and they're going to automatically put you on there and you're not aware of it.

Or you fill it out, no you don't want it, and it never makes it back to them.

- Advantages

In a sense I think it still forces the parent to do something, to take some responsibility even though I agree there are a lot of pitfalls.

- Disadvantages

It's too slippery. Then can always say, well we gave you an opportunity, we sent it in the mail, you didn't give us a response back so we assume you wanted it.

B. *Reactions to "consent" option*

- Consent was the preferred option because respondents believed that it acknowledged them and their right to have a choice in the decision.

You feel you have a say in what's going on.

Specific consent, they would detail that instead of with the opt out, it's a quick end, they just throw this piece of paper at you, do you want this or not?

C. Reactions to “automatic” option

- Respondents found little merit in this option. In fact, it was rejected primarily because it was not believed to offer an option at all. The issue for most was stripping parents of their control of their child's health information.

That's not an option. That's a mandate.

There is no way for you to get out of it. It's like a mandatory sentence. It's no turning back you know.

I think it's a bad idea. One because parents do have privacy issues and it's not fair to them. Two because with the other two methods you have some form of control, albeit small, you have some form of control.

We're in America, you shouldn't have your rights taken away. You should have full disclosure and have some type of say so as to what's going on.

- There was a minority opinion that the automatic option was not all bad. One respondent expressed the opinion that it could be useful for some parents, particularly parents who do not keep records. A misconception was that the name could be removed later.

We've got our books. Well you've got parents [saying], well I don't know if he had a shot or not. Automatic would be good for that type of person but even with the automatic, there should be an ability that once you find out to be able to get out of it and get your child's name off of it.

D. Importance of consent

The reaction of respondents to all of the options reflected the importance they placed on having control of decisions which affect their child. Regardless of how positively they felt about the immunization registry, how the information went into it was a concern. The options seemed to be evaluated in terms of how parents could exercise their rights and make choices.

Because you haven't given up your parental rights. It all goes back to you being in charge of your child. Not only their health, you're talking about health issues, but you being in control of how you're raising the child, so you haven't given up your rights. For automatic or anything else to come into play, they would take away the parental say so, as to what's going to be better for their child.

SECTION 3: ATTITUDES AND PERCEPTIONS OF REGISTRIES

I. Most important benefits of registries

Convenience and a reliable source of information seemed to be the most important benefits to respondents. In addition, they acknowledge the ability of the system to minimize immunization errors.

For the parents that do keep track of the records, they have a back up in case they lose or misplace or whatever. For the parents who don't, they have someplace they can go to get that information.

It could simplify your trip to the doctor. I'm looking at number 3 on the green sheet, for those people who may need day care or can't enter school.

For a doctor other than your child's pediatrician, they're treating your child and they need that information, they have someplace else to go. If your child's pediatrician isn't available, they have another source for that information.

What if, I don't know if it's ever happened, if someone was given the same immunization twice, something of that nature, it could pretty much update their records to help reinforce their record keeping to avoid things like that.

If you're in a situation where it's just the two parents and the child, they move from one state to another and there's no one else in the family and something happens to both those parents at one time. They're going to need to know as much about the child's medical background as they possibly can find.

That's what I was going to say happened to my sister. She didn't keep her son's book and he had to get re-inoculated. I don't want to put my son through that.

You never know what could happen, there could be a fire and you could lose all your records or you can misplace them no matter how organized you are.

II. Greatest concern(s)/biggest risk (s)

- Respondents cited a number of issues which would concern them about the immunization registry for themselves and the public at large. They expressed concerns about potential abuses from insurers and pharmaceutical companies. In addition, they expressed concerns related to how the information could be used to the detriment of African Americans.
 - Exclusion

This is set up for people who are stable, you know household type of situation, but there are people who don't have the stability, who make a point of still taking care of their child's health as best they can. How is this going to work for them?

- Racial Implications

It could be used against you. We're saying that our ethnic people are not getting their well baby care shots, so let's up the premiums.

Males or behavior, they're quick to label your child because of behavior. They are quick to put down, it's a good drug. What, you're talking Ritalin.

- Presumed Consent

I feel as though you shouldn't be pushed into anything. I mean this is far fetched, but this could roll over into other things if it was automatic, it can roll over into anything and everybody says well this is going to be automatic too. Everything becomes automatic not just this health care issue, but other things.

- Respondents were concerned about pharmaceutical companies having access. Unauthorized research and modifying results of studies.

Pharmaceutical companies are very strong, they have a very strong lobby. If they want access to certain things, they get access.

- Respondents were concerned about insurance companies having access. Key issues were cancellation of policies; increase in rates; and refusal of coverage.

- Other concerns were inaccuracy of the input, and misuse of the information

III. Suggestions/comments to people who are responsible for how system works

Respondents suggested that particular attention should be paid to accuracy of information and the safeguarding of information included in the immunization registry.